

ID # _____

FAMILY/CAREGIVER SURVEY

Today's date: ____/____/____

Child's name: _____(1) ____Boy (2) ____Girl

Child's date of birth: ____/____/____

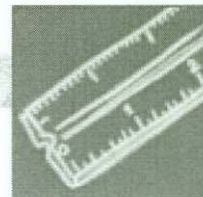
Each of the following questions (unless otherwise stated) refers to right now or in the past 12 months. When questions do not apply to your family or child, circle or write NA (not applicable).

PART I: YOUR CHILD'S HEALTH

1a. What is your child's (most) primary medical condition? (Circle only one)

- | | |
|---|--|
| <input type="checkbox"/> 1. Arthritis | <input type="checkbox"/> 16. Hemophilia |
| <input type="checkbox"/> 2. Asthma | <input type="checkbox"/> 17. HIV/AIDS |
| <input type="checkbox"/> 3. Attention deficit/ hyperactivity | <input type="checkbox"/> 18. Permanent deformity of arms/legs |
| <input type="checkbox"/> 4. Autism/Pervasive developmental disorder | <input type="checkbox"/> 19. Kidney disease |
| <input type="checkbox"/> 5. Blindness/trouble seeing | <input type="checkbox"/> 20. Leukemia/Cancer |
| <input type="checkbox"/> 6. Cerebral palsy | <input type="checkbox"/> 21. Mental retardation |
| <input type="checkbox"/> 7. Chronic ear infections | <input type="checkbox"/> 22. Muscular dystrophy |
| <input type="checkbox"/> 8. Cleft lip/palate | <input type="checkbox"/> 23. Obesity |
| <input type="checkbox"/> 9. Cystic fibrosis | <input type="checkbox"/> 24. Recurrent urinary tract infection |
| <input type="checkbox"/> 10. Deafness/trouble hearing | <input type="checkbox"/> 25. Seizure disorder |
| <input type="checkbox"/> 11. Depression | <input type="checkbox"/> 26. Severe allergies |
| <input type="checkbox"/> 12. Diabetes | <input type="checkbox"/> 27. Severe scoliosis |
| <input type="checkbox"/> 13. Down syndrome | <input type="checkbox"/> 28. Sickle cell disease |
| <input type="checkbox"/> 14. Eating disorder | <input type="checkbox"/> 29. Spina bifida |
| <input type="checkbox"/> 15. Heart disease or heart defect | <input type="checkbox"/> 30. Other (specify below) |







Select from the prior list (1-29) any additional conditions which your child has, write each of them on the lines below. If your child's additional condition(s) are not on the list, please include it/them on the lines below.

a. _____	d. _____
_____	_____
b. _____	e. _____
_____	_____
c. _____	f. _____
_____	_____



CARING FOR YOUR CHILD

The next five questions ask about your child's health needs and whether your child has a health condition. A health condition can be physical, mental or behavioral. Health conditions may affect a child's development, daily function or need for services.

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?

- ☐ Yes  Go to Question 1a
☐ No  Go to Question 2



1a. Is this because of ANY medical, behavioral or other health condition?

- ☐ Yes  Go to Question 1b
☐ No  Go to Question 2



1b. Is this a condition that has lasted or is expected to last for at least 12 months?

- ☐ Yes
☐ No

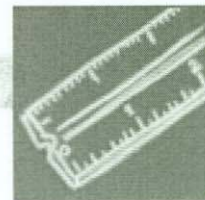
2. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?

- ☐ Yes  Go to Question 2a
☐ No  Go to Question 3

2a. Is this because of ANY medical, behavioral or other health condition?

- ☐ Yes  Go to Question 2b
☐ No  Go to Question 3





2b. Is this a condition that has lasted or is expected to last for at least 12 months?

- ☐ Yes
☐ No

3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?

- ☐ Yes ➡ Go to Question 3a
☐ No ➡ Go to Question 4

3a. Is this because of ANY medical, behavioral or other health condition?

- ☐ Yes ➡ Go to Question 3b
☐ No ➡ Go to Question 4

3b. Is this a condition that has lasted or is expected to last for at least 12 months?

- ☐ Yes
☐ No

4. Does your child need or get special therapy, such as physical, occupational or speech therapy?

- ☐ Yes ➡ Go to Question 4a
☐ No ➡ Go to Question 5

4a. Is this because of ANY medical, behavioral or other health condition?

- ☐ Yes ➡ Go to Question 4b
☐ No ➡ Go to Question 5

4b. Is this a condition that has lasted or is expected to last for at least 12 months?

- ☐ Yes
☐ No

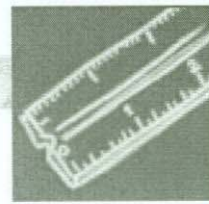
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets treatment or counseling?

- ☐ Yes ➡ Go to Question 5a
☐ No

5a. Has this problem lasted or is it expected to last for at least 12 months?

- ☐ Yes
☐ No





6. Have you been told that your child has a problem that has delayed his or her development? (Development includes motor skills, speech or ability to socially interact with others)

- ☐ Yes
☐ No
☐ Not Sure

7. How old was your child when you first became aware of his/her chronic health condition or disability? _____

(Circle the number below the question that best describes your situation)

8. In general, would you say your child's health is:

- (1) Excellent (2) Good (3) Fair (4) Poor

9. How difficult is it to take care of your child's chronic health condition(s) or disability?

- (1) Not at all difficult (3) Somewhat difficult
(2) A little difficult (4) Very difficult

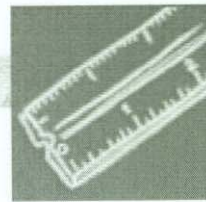
10. During the last 3 months, how often have you worried about your child's health?

- (1) None of the time (4) Most of the time
(2) A little of the time (5) All of the time
(3) Some of the time

11. During the last 3 months, how often have you worried about the impact of your child's chronic health condition or disability upon his or her siblings?

- (1) None of the time (4) Most of the time
(2) A little of the time (5) All of the time
(3) Some of the time (6) NA (not applicable)





12. Do you have any of the following specific concerns for your child?

(Circle the number under the response that best describes your concern)

	Never	Seldom	Sometimes	Often	Always	NA
12a. Growth & development	1	2	3	4	5	NA
12b. Ability to learn	1	2	3	4	5	NA
12c. Falling behind in school	1	2	3	4	5	NA
12d. Making and keeping friends	1	2	3	4	5	NA
12e. Participation in activities of his/her age group	1	2	3	4	5	NA
12f. Learning skills in caring for his/her medical condition	1	2	3	4	5	NA
12g. Being independent	1	2	3	4	5	NA
12h. Ability to make healthy choices (e.g. activity, rest, diet, medicines)	1	2	3	4	5	NA
12i. Self esteem/emotional well being	1	2	3	4	5	NA
12j. The future	1	2	3	4	5	NA
12k. Risky or unhealthy behaviors (e.g. smoking, alcohol use, overeating)	1	2	3	4	5	NA

(Circle the number below the question that best describes your situation)

13. How would you estimate the current overall severity of your child's special health care needs?

- (1) Minimal (3) Moderate
(2) Mild (4) Severe

14. Has there been any change in the past year in the severity of your child's health condition(s) or disability?

- (1) Better (3) Somewhat worse
(2) Same (4) Markedly worse

15. Are things the same from day to day with your child, or is it hard to know what to expect?

- (1) Pretty much the same day to day (3) Lots of unexpected changes
(2) Occasional surprises (4) Very unpredictable one day to the next

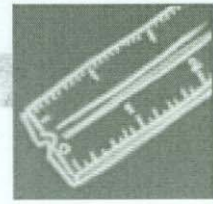
USING THE HEALTH CARE SYSTEM

(Circle the number below the question that best describes your situation)

16. How satisfied are you with the care coordination provided outside of the family that you receive for your child?

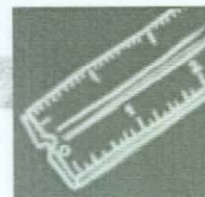
- (1) Very satisfied (4) Very dissatisfied
(2) Somewhat satisfied (5) NA (not applicable)
(3) Dissatisfied





17. During the past year, how many times was your child seen by your primary care provider?
- (1) None at all
 - (2) 1 - 3 times
 - (3) 4 - 10 times
 - (4) More than 10 times
 - (5) NA (not applicable)
18. During the past year, how many times was your child seen by the specialist/ specialty clinic?
- (1) None
 - (2) 1 - 3 times
 - (3) 4 - 10 times
 - (4) More than 10 times
19. During the past year, how many times did your child require care in the emergency room?
- (1) None
 - (2) 1 - 3 times
 - (3) 4 - 10 times
 - (4) More than 10 times
20. During the past year, how many separate times did your child have to stay in the hospital overnight?
- (1) None at all
 - (2) 1 - 3 times
 - (3) 4 - 7 times
 - (4) 8 - 10 times
 - (5) More than 10 times
21. During the past year, what was the total number of nights that your child spent in the hospital?
- (1) None at all
 - (2) 1 - 3 nights
 - (3) 4 - 7 nights
 - (4) 1 - 2 weeks
 - (5) 2 weeks or more
- 22a. In the past 3 months how many days has your child been absent from school because of his/her chronic health condition(s) or disability?
- a. None
 - b. 1 - 5 days
 - c. 1 - 3 weeks
 - d. A month or more
- 22b. Is this typical (as described in # 22a) for school absences during the past year?
- (1) No, the past year has been worse than in the past 3 months
 - (2) Yes, the past year has been about the same in the past 3 months
 - (3) No, the past year has been better than in the past 3 months





23a. In the past 3 months, how many days have you or anyone in your family had to stay home from work because of your child's chronic health condition(s) or disability?

- (1) None
- (2) 1 – 5 days
- (3) 1 – 3 weeks
- (4) A month or more
- (5) No one is employed

23b. Is this typical (as described in #23a) for missed work during the past year?

- (1) No, the past year has been worse than the past 3 months
- (2) Yes, the past year has been about the same as the past 3 months
- (3) No, the past year has been better than the past 3 months
- (4) No one is employed

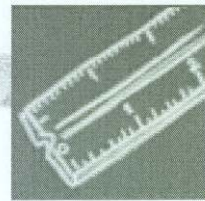
PARENT/CAREGIVER SATISFACTION

Please think about your child's Primary Care Provider(s) (PCP) when responding to each of the following questions.

Circle the answer to the right of each question that best completes the statement (*NA=not applicable).

24. The PCP's skill in managing your child's condition is...	Excellent	Very Good	Good	Fair	Poor	NA
25. The PCP's ability to provide general health care, like the care your child would need for a cold or the flu is...	Excellent	Very Good	Good	Fair	Poor	NA
26. When it comes to helping you coordinate services for your child, the PCP does a(n) _____ job.	Excellent	Very Good	Good	Fair	Poor	NA
27. When it comes to communicating with other professionals about your child's care, the PCP does a(n) _____ job.	Excellent	Very Good	Good	Fair	Poor	NA
28. The PCP's effort to be flexible in the way that he/she works with your family is...	Excellent	Very Good	Good	Fair	Poor	NA
29. The PCP's sensitivity to your family's cultural background and your beliefs about health is...	Excellent	Very Good	Good	Fair	Poor	NA





Circle the answer to the right of each question that best completes the statement
(*NA=not applicable).

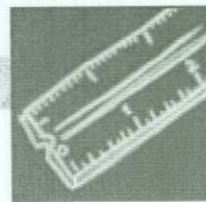
30. When it comes to really listening to your opinions about your child's care, the PCP does a(n) _____ job.	Excellent	Very Good	Good	Fair	Poor	NA
31. The PCP's ability to answer your questions regarding your child's condition is...	Excellent	Very Good	Good	Fair	Poor	NA
32. The amount of information and guidance the PCP gives you to help prevent future problems for your child is...	Excellent	Very Good	Good	Fair	Poor	NA
33. When it comes to referring you to other doctors or services that your child needs, the PCP does a(n) _____ job.	Excellent	Very Good	Good	Fair	Poor	NA
34. The PCP's effort to put you in touch with other parents who have similar concerns is...	Excellent	Very Good	Good	Fair	Poor	NA
35. When it comes to understanding how your child's condition affects your family, the PCP has a(n) _____ understanding.	Excellent	Very Good	Good	Fair	Poor	NA

CARE COORDINATION

Parents of children with chronic health conditions often do a variety of activities to coordinate care for their child. Some parents are new at this, others have been coordinating their child's care for years. Listed below are some of the care activities parents often do. *Please read each activity and circle the response that best describes you and your family today.*

	Always	Often	Sometimes	Rarely	Never	NA
36. Comfortably providing my child the needed medical treatments at home.	1	2	3	4	5	6
37. Involving my child in regular recreational activities in the community.	1	2	3	4	5	6
38. Finding the help I need to coordinate services for my child.	1	2	3	4	5	6
39. Keeping my family life as normal as possible	1	2	3	4	5	6
40. Finding other parents to talk to who have children with similar conditions.	1	2	3	4	5	6



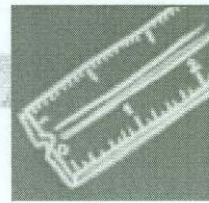


	Always	Often	Sometimes	Rarely	Never	NA
41. Describing how this medical condition affects my child's growth and development	1	2	3	4	5	6
42. Explaining the purpose of medical tests my child receives	1	2	3	4	5	6
43. Understanding the results of those tests.	1	2	3	4	5	6
44. Taking positive action to correct poor care or services my child receives.	1	2	3	4	5	6
45. Getting my child to take an active role in health discussions and in decision making.	1	2	3	4	5	6
46. Telling when my child needs an urgent visit to the doctor or emergency room.	1	2	3	4	5	6
47. Communicating my concerns about my child's health needs to most professionals.	1	2	3	4	5	6
48. Being assertive with health professional about my child's needs	1	2	3	4	5	6
49. Getting the medical care my child needs without difficulty.	1	2	3	4	5	6
50. Getting medical professionals to give us information that we can understand.	1	2	3	4	5	6
51. Able to get competent home nursing care.	1	2	3	4	5	6
52. Able to arrange occasional respite care for my child.	1	2	3	4	5	6

What follows are some questions about visits to your local health care provider's office.
How often does the office/practice provide each of the following?

	Always	Often	Sometimes	Rarely	Never	NA
53. Your health care provider(s) contact your child's specialist(s) as needed?	1	2	3	4	5	6
54. Adequate time is allowed to answer all of your questions?	1	2	3	4	5	6
55. Your health care provider takes an important role in managing your child's chronic health condition or disability visits to the specialists?	1	2	3	4	5	6
56. Your provider asks questions which help you to express your concerns?	1	2	3	4	5	6
57. You get advice on your child's developmental needs?	1	2	3	4	5	6





How would you rate the practice for each of the following qualities?

Please circle one number on each line.

	Excellent	Very Good	Good	Fair	Poor	NA
58. The length of time waiting at the office.	1	2	3	4	5	6
59. Getting help from one of the office staff when you call by phone.	1	2	3	4	5	6
60. Clear directions are provided for who to contact or where to go for different medical problems.	1	2	3	4	5	6
61. Getting through by phone to your health care provider when you need to.	1	2	3	4	5	6
62. Clear directions for who to contact or where to go for aspects of your child's condition when they are not ill.	1	2	3	4	5	6
63. Provider(s) and staff have regular contact with your child's school staff.	1	2	3	4	5	6

FAMILY INFORMATION

(Circle the number below the question that best describes your situation)

64. How many additional children live in your home?

(1) None (2) One (3) Two (4) Three (5) Four (6) Five (7) Six or more

65. What is the employment status of your

65. Child's Mother?

- (1) Full-time homemaker
- (2) Part-time employed
- (3) Full-time employed
- (4) Not working, but looking for work
- (5) Non-salaried volunteer
- (6) Retired
- (7) Unable to work due to mother's disability
- (8) Unable to work due to child's condition
- (9) Other (specify)

66. Child's Father?

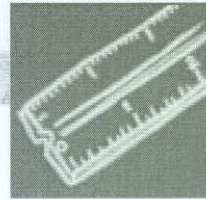
- (1) Full-time homemaker
- (2) Part-time employed
- (3) Full-time employed
- (4) Not working, but looking for work
- (5) Non-salaried volunteer
- (6) Retired
- (7) Unable to work due to father's disability
- (8) Unable to work due to child's condition

(9) Other (specify)

67. Please estimate your total family income (before taxes):

- (1) over \$100,000
- (2) \$50,000 to \$99,999
- (3) \$25,000 to \$49,999
- (4) \$10,000 to \$24,999
- (5) less than \$9,999
- (6) skip





68. Do you have health insurance for yourself? (1) Yes (2) No (3) Don't Know
69. Do you have health insurance for your child? (1) Yes (2) No (3) Don't Know
70. Do you have Medicaid support for your child? (1) Yes (2) No (3) Don't Know
71. Do you have supplemental security income? (1) Yes (2) No (3) Don't Know
(SSI Support)
72. Do you receive any other assistance
from the state (e.g., special medical services)? (1) Yes (2) No (3) Don't Know
73. Do you have regular out-of-pocket health expenses
(over \$25/month or \$300/year) to care for your child's
health condition or disability (excluding insurance
deductibles or co-payments)? (1) Yes (2) No (3) Don't Know
74. Are out-of-pocket expenses mostly related to:
- | | | | |
|---------------|--------------------|------------------|----------------|
| (1) Equipment | (3) Medications | (5) Counseling | (7) Other_____ |
| (2) Supplies | (4) Family support | (6) Respite care | |

COMMENTS:

Use the remaining space to express your thoughts about this survey or any of the areas it has caused you to think about.

Thank you for your help and time completing this survey.

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